Hearing the Voice of the PERSON with dementia

Sonya Barsness and Karen Stobbe
Who are you?

Find 5 things that everyone at your table has in common
I'm glad we're on the same page.

Symptoms of Dementia

Module 1: Understanding the World of Dementia
Every person is an individual.

Our Guiding Values

CAN’T → HOW
Every person has a right to their best life.

We MUST Change

CHANGE BEGINS WITH me.
Person-Centered Care values choice, dignity, respect, self-determination and purposeful living.

Person-Centered Care honors an individual's goals and preferences. Specifically with dementia, this approach looks past the diagnosis to the person, emphasizing communication and relationships between caregivers and residents.

Break down Barriers

Us  Them
They  We
Every person has a voice.

**Being with Persons with Dementia Means...**

- Understanding things from their perspective.
- Being with persons with dementia “where they are”.
- Recognizing persons with dementia as whole individuals.

**Being with Persons with Dementia Means...**

- Building on strengths.
- Connecting with persons with dementia and validating them as human beings and as equals.
- Recognizing that sometimes the best way we can support persons with dementia is to just be with them, to sit with them, and to listen to them.
How do we hear the person?

Asking
Listening
Hearing
Watching
Knowing
Being

to listen

PREPARED BY KAREN STOBBE & SONYA BARSNESS
“I’ve been trying to listen to you, but you haven’t been saying anything interesting about me.”

Most people do not listen with the intent to understand. They listen with the intent to reply.

We spend 60% of our time listening
But only retain 25% of what we hear
What can you “hear” with your eyes?

video

"It can't get away from me... if I am in this place".
If I really try and think what time means to me now, it’s like flickering images. It’s something I might see in the calendar that I did a few weeks ago and then there’s something I might do in a week or so, or things I’ve done today or might do later. It’s just like flickering images. It’s not really a flow of time. Nor can I make sense of it.

So if people say, “What did you do yesterday?” I have to look at the diary, I see what I did yesterday and it’s what’s in the diary, it doesn’t feel as if it really happened. I don’t really connect with it because there isn’t a thread linking me back to it.
Most days I feel like I’m clinging to the precipice with my fingernails. I know there’s that looming black hole somewhere down there which is, you know, decline and despair, I don’t want to go there. So I’m clinging on with every bit of effort I’ve got to try and keep going, keep functioning, to keep speaking, keep rewiring.

In order to have this façade of normality it takes a huge amount of effort. So only really Paul probably knows what it’s like, you know, afterwards when I just have to just rest because it’s just taken so much out of me to behave like a normal person.

I am determined to practice deep listening. I am determined to practice loving speech.

Thich Nhat Hanh
More Than Words: Scenario 1

Instructions:
You may only use facial expressions and body language. You may not use words or noises.

Message you want to send:
I have finished eating.
I want to go lie down for a nap.
More Than Words: Scenario 2

Instructions:
You must only use gibberish. You may NOT use understandable words. You may NOT use gestures or body language.

SAY: Ebby bopo shoogy ma-kaa-daaa

Message you want to send:
I need to go to the bathroom.

Listen to not just the words but the:

Body language
Facial expressions
Tone & Inflection of voice
Emotional content

When you hear the word behavior what comes to mind?
CHALLENGING
Difficult
BAD
Manage
Inappropriate

KICKING
spitting
Yelling
Eloping
HITTING
hoarding
uncooperative
Wandering
Aggressive

Behaviors
=  
Actions & Reactions
Actions and Reactions ...

- Are a form of communication
- Can be an expression of a need
- Can be a response to our poor “behavior”

Reasons Behind Actions and Reactions

<table>
<thead>
<tr>
<th>Health Conditions</th>
<th>The task</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaions</td>
<td>Unmet Needs</td>
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<tr>
<td>Communication</td>
<td>Life Story/Personality</td>
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<td>Environment</td>
<td>YOU</td>
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Health

- Medications
- Constipation
- Dehydration
- B12 deficiency
- Depression
- Fatigue
- Discomfort
- UTI
- Sick; a cold or flu
- Pain
- Chronic illness
- Impaired senses
Communication
- No eye contact
- Poor approach
- Talking to fast
- Not listening to them
- No patience
- Body language not matching your words

Task
- Not appropriate for their ability
- Too many steps
- It is unfamiliar
- Not communicated correctly

Environment
- Too large
- Too unfamiliar
- Poor sensory environment
- Too much stimulation; loud/busy
- Too unstructured
Unmet Needs

- Comfort
- Attachment
- Occupation
- Identity
- Love

Life Story

- What was the person’s occupation/s?
- What did they like to do?
- What were their fears?
- Was there trauma in their life?
- What made them happy?

You
If we had a pill that made “behaviors” of people with dementia disappear, would this solve the “problem”? 

Five Reasons to Move from Non-Pharmacological to PCC

1. Non-pharm medical lens
2. Need to see behaviors as form of communication
3. Overlooks other outcomes
4. Have value but do not transform the underlying environment/experience
5. Focus on disease rather than person
If you had no short-term memory and you struggle with concentration and word finding

A person came into your room, opened your drapes and pulled your blankets down and said, "Sonya, It's time to get up."
If you have no short term memory and have lost your social graces...

Someone is in your home and they have long beautiful hair so you walk up and say how pretty they are and look like your sister and you stroke their hair. Then someone you do not recognize comes up and tells you that is inappropriate.

What is normal to a person with dementia?

Reacting to what seems to be abnormal behavior of others

“The shift from the old culture to the new is not a matter of adding on a few items that were missing, but of seeing almost every feature in a different way.”

-Tom Kitwood, Dementia Reconsidered
Every person has needs.
Research on Unmet Need

RCT- Compared two groups of residents with dementia
One group had individualized approaches specific to their identified unmet needs.
Other group just had educational presentation on agitation, behaviors, etc.
Intervention group had significant decreases in agitation, aggression, and increases in pleasure.


Identity

having a history
individuality
well-known
personhood
I am struck by comments about what a person with dementia can and cannot do, realizing that there are many things a person can do, even with dementia. When you have dementia, other people are always making this distinction for you - what you can and cannot do - and you are often not given the chance to determine it for yourself.

- Person with dementia

Identity

How many roles do you have?
The next time you communicate with someone who is not at his or her cognitive best, remind yourself of this:

“This interaction is not about me. This interaction is about someone who is seeking connection on terms that may not advance the interests or needs of my ego. I am going to go where your needs are taking you. I am going to be with you in that place, wherever and however it is. I am going to let my ego disappear now. I am going to love you in your image instead of trying to re-create you in mine.”

Michael Verde, President, Memory Bridge

Identity

When I’m 64 84

Where will you live?
With anyone?
What do you like to do?
What are your hopes? dreams?
What if that was written on a chart with other negative things about yourself?

- Wanders constantly. Cannot sit still
- Has tendencies to take others belongings
- Is not patient – may get irritated or aggressive if made to wait too long
- Has intense muscle pain and can have spasms
- Has bursitis in knees
- Has arthritis in neck and upper back due to cervical kyphosis
• Will only join in group activities once in a while. Tends to like to be the center of attention or be alone.
• Has abnormal fear of birds
• Had a speech impediments as a child.
• Roams into kitchen at all times of the day
• Has carpal tunnel syndrome and may not be able to use dominant hand

Comfort

Soothing
Security
Warmth
Safe
Relaxed
Oh, the comfort — the inexpressible comfort of feeling safe with a person — having neither to weigh thoughts nor measure words, but pouring them all right out, just as they are, chaff and grain together; certain that a faithful hand will take and sift them, keep what is worth keeping, and then with the breath of kindness blow the rest away.

~ Dinah Craik, A Life for a Life, 1859
We say, “This is your home.”

Is it, really?

What makes a home?

Meaning of Home

Physical home
Social Home
Personal Home

- Judith Sixsmith (1986)

"Home is a central emotional and sometimes physical reference point in a person’s life"
Empowering

"Home is a place that highlights personal strengths and enables feeling of accomplishment, independence, responsibility, and usefulness."


Meaning of Home

Refuge

"...home as a place of comfort, safety, ownership, and insideness."
"...fewer restrictions than the outside, public world."


Meaning of Home

Relationship

“togetherness”
“social insideness” from “‘a reservoir of accumulated social credit’ derived from contributions made to the community over time”

Meaning of Home

Being known

"Home is a place where the self is recognized, significant, and known."


Meaning of Home

Self-Reconciliation

"...require significant efforts to redefine, reconcile, re-narrate, and reconfirm the meaning of "me" in the new environment."


Meaning of Home

Integration

"person-place integration as ‘feeling a part of life’” and ‘being in meaningful relationship’”

When person and place disengaged, social withdrawal happens

What gives you that at home *ahhhhhhhh*?

“It’s good to be home”

Each of you take 3 Sticky Notes
Inclusion

Acceptance
Part of a group
Being engaged with others
Connection
“Exclusion has an impact on the self. People with dementia experience feelings of embarrassment and stigma, their sense of self and self-esteem is negatively affected, and they experience loss of dignity, stress, and distress.”

From “DEMENTIA AND SOCIAL INCLUSION: MARGINALISED GROUPS AND MARGINALISED AREAS OF DEMENTIA RESEARCH, CARE AND PRACTICE” - ANTHEA INNES, CAROLE ARCHIBALD, CHARLIE MURPHY

POWerPOINT PREPARED BY SONYA BARSNESS AND KAREN STOBBE 2014, HAND IN HAND CO-DEVELOPERS.

Ubuntu

I AM BECAUSE YOU ARE
“I define connection as the energy that exists between people when they feel seen, heard, and valued; when they can give and receive without judgment; and when they derive sustenance and strength from the relationship.”

-Brene Brown

How do we include people with dementia?
Occupation

Purpose
Control
Doing what is important to you.

Becoming engaged, staying involved in a purpose, in purposeful activities is a key to living out our lives as happy, fulfilled individuals.

Richard Taylor
What give you purpose?

If you had no one expecting you

Why leave your house?
Why leave your room?
Why get out of bed?
"I need you."

Are we giving people with dementia purpose or are we keeping people busy?

Attachment

Connections
Trust
Nurture
Relationship
When I am with someone with whom I have a relationship, I know that I am living. But, surrounded by people who are strangers, funneled into daily routines that are unfamiliar and uncomfortable, my life unknown to others, I'm not sure I am alive.

It’s as though I have fallen out of life — perhaps into a living death... relationships are not only the heart of long-term care, they are the heart of life. And life ought to continue, wherever we live.

by Carter Catlett Williams, MSW, Convener of The Pioneer Network
...Relationships are not only the heart of long-term care, they are the heart of life. And life ought to continue, wherever we live.

Google relationship and Alzheimer's

Cortical signatures of cognition and their relationship to...
Till Dementia Do Us Part: Alzheimer's Caregivers, Spouses...
Changes in Relationships...
Changing Roles and Relationships...
Brain-Behavior Relationship – Alzheimer’s Disease
Trouble with our visual or spatial relationships...

Simply put the philosophy suggests that what a person with dementia needs most of all is a friend, a “Best Friend.” This can be a family member, friend, or staff member who empathizes with their situation, remains loving and positive, and is dedicated to helping the person feel safe, secure and valued.

Virginia Bell, MSW
David Troxel, MPH
Why is relationship important?

Residents/clients and their family members consistently value the quality of their relationship with staff over other aspects of care. (Eaton 2000; Bowers, Fibich, & Jacobson 2001) Staff say their relationship with residents/clients is what keep them committed to their jobs (Castle 2007, Bowers 2003)

From "Consistent Assignment: Cultivating Caring Relationships" by PHI

Theory of relational coordination

Relationships with the client are shaped by the relationships among all those who are caring for the client. It is the community of relationships that shapes the client experience.

-Jody Hoffer Gittell, Brandeis University

Trust is the glue of life. It's the most essential ingredient in effective communication. It's the foundational principle that holds all relationships.

-Stephen R. Covey
“The gerotranscendent individual, as we shall see, typically experiences a redefinition of self and of relationships to others and a new understanding of fundamental, existential questions. The individual becomes, for example, less self-occupied and at the same time more selective in the choice of social and other activities.

There is an increased feeling of affinity with past generations and a decrease in interest in superfluous social interaction. The individual might also experience a decrease in interest in material things and a greater need for solitary ‘meditation’. Positive becomes more important. There is also often a feeling of cosmic communion with the spirit of the universe, and a redefinition of time, space, life, and death.”

What gives us purpose earlier in life

May or may not give us purpose later in life
A few things we have been thinking about

Buy In into Inclusion

We talk about getting 'buy in' from staff, from administrators, from board members, from anyone who is not in the room.

Buy in insinuates that you need a group of people to agree with what you are doing. Instead we need to all be included in the original ideas.
Is Behavior a Symptom of Dementia?

LaQuisha
What are three take aways?

THE PEOPLE WHO ARE CRAZY ENOUGH TO THINK THEY CAN CHANGE THE WORLD ARE THE ONES WHO DO.

[Image of rocks]
Thank you.
We appreciate your time and the work you do.

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